BFSS 2011 Conference

Hope, Faith, and Care: Rising to the Challenge of FASD

A Summary of the Plenary and Breakout Sessions of the Building FASD State Systems Conference and Affiliated Meetings

Phoenix, Arizona • May 11-13, 2011

Report submitted: June 13, 2011

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Electronic versions of the majority of the presentations summarized herein are available on the FASD Center for Excellence Web site (www.fasdcenter.samhsa.gov).

BFSS 2011 Conference: Background and Planning

History

The Substance Abuse and Mental Health Services Administration (SAMHSA) Fetal Alcohol Spectrum Disorders (FASD) Center for Excellence (the Center) convened the eighth Building FASD State Systems (BFSS) Conference May 11–13, 2011, in Phoenix, Arizona. This annual event supports the Center's legislative mandate to provide technical assistance (TA) to communities developing systems of care, and is designed to further specific Center goals, including:

- Advancing the field of FASD
- Facilitating the development of comprehensive systems of care for FASD prevention and treatment
- Building infrastructures to ensure that FASD gets critical resources required for lasting change
- Identifying components of a comprehensive system of care for individuals who have an FASD
- Incorporating evidence-based interventions and prevention practices

This year's conference included an additional round of breakout sessions and, for the first time, a unique track for members of the **Self Advocates with FASD in Action Network** and their support persons.

Attendees

A wide range of participants are invited to BFSS each year, with an emphasis on State and U.S. Territory government employees involved in issues related to FASD and policymaking. The sessions include voices from across the entire spectrum of support and services to people with FASD, including representatives from primary care, the public and private sectors, criminal justice and social service, birth mothers and family members, individuals with an FASD, advocates, counselors, educators, administrators, mental health and substance abuse treatment professionals, researchers, and scientists.

BFSS 2011
Attendees at-a-Glance

Participation at this year's conference represented a 20 percent increase from the 2010 conference. There were **230 participants** from:

- **49 States** and the District of Columbia
- **2 U.S. Territories** (Virgin Islands and Northern Mariana Islands)
- **Native American Communities**

This year's sessions featured representatives from 49 States (North Dakota was not represented), two U.S. Territories (Virgin Islands and the Northern Mariana Islands), Washington, D.C., and the Navajo Nation. Attendees included local, State, and juvenile court subcontractors implementing FASD intervention programs, as well as members of the Center's Expert Panel, the American Indian/Alaskan Native/Native Hawaiian Expert Panel (Native Expert Panel), the National Association of FASD State Coordinators (NAFSC), the Birth Mothers Network (BMN), and the newly formed Self Advocates with FASD in Action (SAFA) Network. Other agencies represented included the National Organization on Fetal Alcohol Syndrome (NOFAS), the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS), The Arc of the United States, Children and Families First, Prevention First, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Centers for Disease Control and Prevention (CDC), as well as representatives from universities throughout the country.

Planning the Conference

Each year, a BFSS Planning Committee helps formulate the conference agenda and activities. This Committee consists of individuals from the field, working with the SAMHSA Contracting Officer Technical Representative (COTR), SAMHSA Alternate COTR, and staff from the Center. The Committee meets by teleconference as often as necessary—this year there were four meetings—to accomplish the needed tasks. In selecting Planning Committee members, Center staff looks for representation from:

- Diverse geographic locations
- States at all levels of FASD systems development
- Various organizations
- States that have received a local community and/or State subcontract, as well as non-funded States
- A mix of cultures and ethnicities
- The meeting's host State
- Previous Planning Committee members

The BFSS 2011 Conference Planning Committee began working in January 2011. They developed the conference theme and reviewed and recommended plenary and breakout session topics and potential speakers. Many Committee members also introduced speakers and served as session moderators and panelists at the conference.

BFSS 2011 Planning Committee

- Louise S. Ashkie (The Navajo Nation)
- Shelly L. Bania (Michigan)
- Cynthia D. Beckett (Arizona)
- Peggy S. Combs-Way (California)
- Leigh Ann Davis (Texas)
- Danielle Glenn-Rivera (California)
- Bernestine Jeffers (Wisconsin)
- Teresa J. Kellerman (Arizona)
- Sara Messelt (Minnesota)
- Laura M. Nagle (Kentucky)
- Melinda S. Norman (Ohio)
- Isabel M. Rivera-Green (Delaware)

Phoenix, Arizona, was chosen as the site for BFSS 2011 Conference because of its location, adequate meeting space and accommodation availability, and competitive pricing. As the theme for this year's event, the Planning Committee chose *Hope, Faith, and Care: Rising to the Challenge of FASD* to tie in the image of the mythical phoenix that rises from ashes to live again and the need for hope, faith, and care to apply to the challenges in the field of FASD.

This year, for the first time, the Center sent out a call for abstracts for the conference. The Center received 44 abstracts for presentations—43 after one was withdrawn. The Planning Committee reviewed the Center's top selections and gave their recommendations on ways to maximize the number and diversity of presentations (e.g., by adding another round of breakout sessions and combining speakers into broadly themed panels).

CONFERENCE OVERVIEW

Registration, First-Time Attendees' and Mini Training Sessions, Poster and Exhibit Displays—Wednesday, May 11, 2011

BFSS participants were able to register for the conference beginning at 3:30 PM on Wednesday, May 11. Later that afternoon, interested participants attended *We're Glad You're Here: BFSS First Time Attendees' Session*, presented by the Center's Project Director, Callie B. Gass. Afterward, Dan Dubovsky, MSW, the Center's FASD Specialist, presented a well-attended FASD mini training titled *Is Accurate Diagnosis Necessary? Behavioral Issues in FASD*. Beginning at 5:30 PM on the same day, the Center staged the annual opening of the Poster and Exhibit Display Session, during which the Center's 23 subcontractors and other presenters shared posters and other materials about the FASD activities in their States. Morgan Fawcett, a Native American flute player, provided music during the session and shared information about his music, his passion for FASD advocacy, and his collection of beautiful handmade flutes. Attendees were able to use this session as a learning and networking opportunity.

BFSS Conference—Structure of the Sessions

As in previous years, the conference included general plenary sessions attended by all participants, followed by breakout sessions that allowed participants to select topics that suited their needs and interests. There were two rounds of breakout sessions on the first day, with five topic-specific sessions during each round—one session per round was a closed session for SAFA members and their support persons. On the second day of the conference, five additional topic-oriented breakout sessions were presented—one of these sessions was also a closed session for SAFA members and their support persons. Brief descriptions of the plenary sessions are provided below. Listings of the breakout sessions offered on each of the two meeting days follow.

Day 1 Plenary Sessions—Thursday, May 12, 2011

Opening Welcome

Ernest Harry Begay, Traditional Practitioner, Navajo Regional Behavioral Health Board, New Mexico

The BFSS Conference began Thursday, May 12 at 8:30 AM with an opening by Mr. Begay. He told a traditional story of a flood and those who came forth to lead people to safety. He noted that FASD is like the flood and compared the conference attendees to the leaders in the story, saying that through their expertise and use of faith, hope, and care, they provide leadership to the field.

Introduction and Welcome on Behalf of SAMHSA

Jon P. Dunbar-Cooper, MA, CPP, COTR, SAMHSA FASD Center for Excellence, Public Health Analyst, Center for Substance Abuse Prevention (CSAP), SAMHSA

On behalf of SAMHSA, Mr. Dunbar-Cooper thanked members for coming to the conference to learn from their peers and share their expertise. He also thanked the Planning Committee for their good counsel and hard work. He noted that participants will be provided with information on many of the components necessary to build comprehensive statewide FASD systems of care.

Keeping the Faith: Time to Hear from Dads of Children with FASD

Moderator: Dan Dubovsky, MSW, Parent, FASD Specialist, SAMHSA FASD Center for Excellence

Speakers:

- Michael O'Connor, Parent, Advocate, New York
- Ted Wybrecht, Parent, Advocate, Retired Educational Consultant and Evaluator, Michigan
- Gene Wright, Parent, Advocate, Hawaii

Mr. Dubovsky spoke with a panel of three fathers of children with an FASD, who shared stories of the joys and challenges of parenting, the support networks they created, and the things they learned from their children (e.g., try *differently* instead of *harder*). Each panel member credited their wives for creating needed organization and structure for their children, underscoring the value of collaborative effort for parents of a child with an FASD.

Rising to the Challenge: Report from the SAMHSA FASD Center for Excellence

Callie B. Gass, Project Director, SAMHSA FASD Center for Excellence

Ms. Gass provided participants with an update on the Center's major activities, highlighting the development of the SAFA Network and four other FASD-related learning communities:

- FASD Prevention and Treatment: Addressing Race, Ethnicity, and Culture in Service Delivery
- State Systems Learning Community
- Medical and Psychological Diagnostic Learning Community
- FASD Programs Learning Community

The Center has supported the expansion of **Learning Communities**—groups of individuals who share a common focus and are engaged in learning from one another.

The Center's ongoing growth and success are also reflected in (1) widespread provision of training and TA events, including assistance with the development of strategic plans, modification of treatment for individuals with an FASD, and updates for others training on FASD in the field, (2) ongoing updates to and extensive use of the information available through the Center's official Web site (www.fasdcenter.samhsa.gov) and its toll-free hotline (866-STOPFAS), and (3) the assistance and resources offered through the Service-to-Science Initiative to FASD-focused programs with strong reputations.

As Ms. Gass noted, the Center also continues to raise the profile of issues related to FASD by:

- Providing presentations and/or displaying posters at conferences and other events;
- Developing a Treatment Improvement Protocol (TIP) addressing FASD in substance abuse treatment settings; and
- Supporting activities under the Center's Native Initiative that both respect and benefit from the wisdom of these diverse communities (e.g., updating the Native Resource Kit, planning for three Native Leaders conferences, and providing TA events specific to Native American communities).

Opening Notes: SAMHSA Updates with a Focus on Partnerships

Introduction: Patricia B. Getty, PhD, Alternate COTR, SAMHSA FASD Center for Excellence; Branch Chief, Division of Systems Development (DSD), CSAP, SAMHSA

Speaker: Virginia Mackay-Smith, MPH, Director, DSD, CSAP, SAMHSA

Ms. Mackay-Smith shared information on how changes within SAMHSA and other factors (e.g., changes to the nation's health care system) may affect future work in the field of FASD. One key change within SAMHSA is the adoption of eight strategic initiatives to guide work across its three Centers—the Center for Substance Abuse Treatment, CSAP, and the Center for Mental Health Services. SAMHSA is working to integrate behavioral health into each of its initiatives—recognizing it as essential to overall health and in lowering costs for families, businesses, and governments. Also key to SAMHSA's message of hope is that prevention works, treatment is effective, and people recover.

SAMHSA's Eight Strategic Initiatives

1. Prevention of Substance Abuse and Mental Illness
2. Trauma and Justice
3. Military Families
4. Recovery Support
5. Health Reform
6. Health Information Technology
7. Data, Outcomes, and Quality
8. Public Awareness and Support

With respect to health reform, Ms. Mackay-Smith noted that it stands to:

- Enhance access to health care, including prevention and treatment services for mental illness/substance use disorders;
- Provide more control for consumers;
- Require more accountability for insurance companies;
- Improve health care for persons living with disabilities; and
- Reward high-quality care and reduce waste, fraud, and abuse.

In looking toward the future, Ms. Mackay-Smith encouraged participants to:

- Seek out partnerships;
- Follow changes related to health reform;
- Look for opportunities at the State-level to insert FASD into the change process;
- Rely on data;
- Tell human stories; and
- Capitalize on experience.

Finding Hope: Current Science and Research Trends in the Field

Introduction: Catherine A. Hutsell, MPH, Health Education Specialist, FAS Prevention Team, CDC

Speaker: Susan M. Smith, PhD, President, FASD Study Group; Professor, Department of Nutritional Sciences, University of Wisconsin-Madison

Dr. Smith provided current science and research trends in FASD, noting several recent studies to counter challenges to the prevention of FASD (e.g., lack of hard numbers on the scope and cost of the problem, public perception of moderate drinking risk for pregnant women). With respect to diagnosis and detection, a collaborative initiative is working to develop common terminology for FASD data and to pool data from 16 different centers in order to create a large data cohort for research and study. The goal of this initiative is to use the pooled information to develop effective diagnostics, interventions, and treatments. Craniofacial dysmorphology, identification of unique structural defects, and surface-based morphometry are all being used to quantify physical differences to find reliable and cost-effective methods for diagnosis. In addition to using

external physical differences in diagnosis, researchers are also looking at biomarkers and behavioral profiling as ways in which an FASD diagnosis may be confirmed.

Dr. Smith also discussed findings from studies that looked at better understanding the teratogenic effects of alcohol on the brain. Findings include:

- Both verbal and non-verbal memory are reduced in those prenatally exposed to alcohol, resulting in problems with encoding memory.
- The brain works harder (i.e., more regions of the brain are engaged) in individuals with an FASD.
- Brain functioning in individuals prenatally exposed to alcohol appears to improve as children grow.

With regard to promising interventions, Dr. Smith highlighted a study that showed choline supplementation in animal studies to improve post-natal working memory in those prenatally exposed to alcohol.

Day 2 Plenary Sessions—Friday, May 13, 2011

Linking Care and Support: Collaborative Prevention Across Colorado Bringing Evidence-Based Guidelines and Research into Practice

Moderator: L. Diane Casto, MPA, Manager, State of Alaska, Behavioral Health Prevention and Early Intervention Services; National Prevention Network Vice President of External Affairs; Expert Panel Member; NAFSC Member

Speakers:

- Pamela Gillen, RN, ND, CACIII, COFAS Prevention Project Director, Colorado AHEC System, Anschutz Medical Campus, University of Colorado Denver; Expert Panel Member; NAFSC Member
- Thea B. Carruth, MPH, Senior Project Manager, Team HealthWorks
- Brie Reimann, MPA, Project Director, Peer Assistance Services

Three professionals discussed aspects of the collaborative FASD prevention system in Colorado. Dr. Gillen shared some of the geographic and cultural challenges of prevention outreach in Colorado, noting that Colorado ranks higher than the national average with women of childbearing age drinking alcohol 3 months prior to pregnancy (68%). To address this risk, several organizations across Colorado joined together to prevent FASD and promote wellness in women and individuals who are affected by FASD. These organizations include:

- The COFAS program at the University of Colorado Anschutz Medical Campus;
- The Healthy Women Healthy Babies Roundtable at the Colorado Department of Public Health and Environment;
- Health Team Works, a nonprofit organization in Denver that develops 1-page evidence-based guidelines with accompanying tools (e.g., screening questionnaires, care flowsheets); and
- SBIRT (Screening, Brief Intervention, and Referral to Treatment) Colorado, a subcontract funded by SAMHSA.

Presenters discussed methods used to support healthcare settings in implementation of evidence-based practices, such as:

- Development of 1-page guidelines on prevention, SRIRT, FASD, preconception, and contraception and use of the Rapid Improvement Activity to train practice teams on the guidelines;
- Online training modules on tobacco, alcohol, and other drug implementation; and
- SBIRT Colorado hospitals trainings.

Creative Solutions for Sustainability—The Mississippi Experience

Introduction: Teresa Kellerman, Director, FAS Community Resource Center; SAFA Network Support Person; NAFSC Member; BFSS Planning Committee Member

Speaker: Trisha Hinson, MEd, CMHT, FASD State Coordinator/State Project Director, Mississippi Department of Mental Health; NAFSC Member

Ms. Hinson discussed sustainability as *connecting the dots*, which she defined in part as amassing resources and identifying strengths. Key to Mississippi's FASD system of care is legislated MAP (Making A Plan) Teams, which identify needed community-based services and resources while facilitating the provision and coordination of services across agencies. This is accomplished by using interagency agreements between the MAP Team and the members serving on the team. Membership in each MAP Team reflects its community resources and typically involves representatives from families, schools, Community Mental Health Centers, Family and Children Services, Departments of Rehabilitation Services, Health Departments, law enforcement, Youth Court, ministers, youth leaders, and other relevant stakeholders. Ms. Hinson mentioned the following as key to a comprehensive FASD system of care:

- Strategic planning to identify what is needed;
- Raising FASD awareness;
- Creating an FASD Advocacy Council and subcommittees with meaningful work; and
- Making policy and legislative changes (e.g., standards of care, screening requirements).

In closing, Ms. Hinson reminded participants that things that are worthwhile and lasting take time to develop.

Day 1 Breakout Sessions—the First Round

On Day 1, participants chose one of four breakout sessions in each of two rounds. SAFA Network members and their support persons attended closed sessions specifically developed for their group.

Day 1: The First Round of Breakout Sessions

- Spreading Wings: Developing Diagnostic Capacity in Your State
- Soaring to New Heights: Testing the Feasibility of Screening Children for FASD Risk in Early Intervention Settings
- Rising from the Ashes: Preventing FASD by Creating a Circle of Hope
- Hope and Action: Shaping Policies to Sustain Strategies that Prevent and Address FASD
- The VOICE of the SAFA Network (a session for SAFA Network members and their support persons)

Spreading Wings: Developing Diagnostic Capacity in Your State

Moderator: Isabel M. Rivera-Green, MSW, CPS, Prevention Specialist, Delaware Division of Substance Abuse and Mental Health; National Prevention Network Member; BFSS Planning Committee Member

Speakers:

- Sara Messelt, Executive Director, MOFAS; BFSS Planning Committee Member
- Mary Jo Hofer, Diagnostic Specialist, MOFAS

MOFAS was founded in 1998 with the mission of eliminating disability caused by alcohol consumption during pregnancy and improving the quality of lives for those living with FASD throughout Minnesota. Through a sole source grant from the Minnesota Department of Health they created a Diagnostic Work Group which evolved into the Diagnosis Consortium, which brings together diagnosticians, clinicians, and administrators charged with increasing diagnostic capacity in the State through collaboration, education, problem-solving, and advising MOFAS.

Minnesota currently has eleven diagnostic centers across the State. There is not one formula for a diagnostic team, but the key to success is to have a medical provider who is a champion for FASD and owns the process, a skilled and dedicated team of professionals on staff, coordination of services with other multidisciplinary staff, competent support staff who aid in the coordination of services, and "open" slots for the diagnostic evaluation.

Minnesota is currently working with four major institutions in the State to add an FASD screen to "Well Child" visits supported through both Medicaid and private insurance. These children will be followed and tracked for symptoms. Once symptoms appear in a child, he/she will be provided with early intervention services, whether or not the individual has been through the diagnostic process.

Soaring to New Heights: Testing the Feasibility of Screening Children for FASD Risk in Early Intervention Settings

Moderator: Bernestine Jeffers, Women's AODA Treatment Coordinator, Bureau of Prevention Treatment and Recovery, Division of Mental Health and Substance Abuse Services, Wisconsin Department of Health Services; BFSS Planning Committee Member; NAFSC Member

Speakers:

- Enid Watson, MDiv, Director, Screening & Early Identification Projects, Institute for Health & Recovery; Massachusetts State FASD Coordinator; NAFSC Member
- Norma Finkelstein, PhD, LICSW, Executive Director, Institute for Health & Recovery; Expert Panel Member

Presenters discussed the need for and benefits of early screening and intervention, noting that in order for children with FASD to receive the full benefit of services, recognition of their condition needs to be made earlier and more accurately than is common today. Early identification of an FASD helps to focus targeted treatments, reduces unnecessary medical steps and redundancy in medical care, and increases the likelihood of effective intervention. The presenters described an innovative brief screening tool designed to test the feasibility of screening for FASD risk in early intervention settings. This tool can be used by non-clinical staff with moderate training; the only technical need is a paper tape measure for head circumference and a gender- and age-specific growth chart against which to determine if head size is below the 10th percentile. Presenters also shared training needs, barriers encountered during implementation and strategies to address them, and recommendations for linkage development/enhancement. The following article provides findings and lessons learned:

Watson, E., Finkelstein, N., Gurewich, D. & Morse, B. (2011) The feasibility of screening for FASD risk in early intervention settings: A pilot study of systems change. *Infants and Young Children*. April/June (24:2).

Rising from the Ashes: Preventing FASD by Creating a Circle of Hope

Moderator/Speaker: Kathleen T. Mitchell, MHS, LCADC, Vice President and National Spokesperson, NOFAS; BMN Project Director; Expert Panel Member

Speakers:

- Sue Terwey, MS, Program Director, MOFAS; BMN Member, Minnesota
- Naomi Michalsen, Executive Director, Women in Safe Homes; BMN Member, Alaska
- LaShaunda Harris, Clinical Supervisor, Yakima Parent-Child Assistance Program (P-CAP) Program, Triumph Treatment Services, BMN Member, Washington

Ms. Mitchell provided an overview of the mission of NOFAS and the results of a recent demographic survey among a small sampling of birth mothers. She shared that the NOFAS and Center-sponsored Birth Mothers Network includes 12 State/Regional Coordinators and 16 active speakers in the BMN Speakers Bureau. The panelists then took turns sharing their stories. The key themes that emerged were:

- Birth mothers reach out to other moms in recovery to provide courage and support;
- Multigenerational influences can lead to substance use problems among women;
- It is important for women to recognize and move past the stigma associated with being a birth mother;
- Hope exists for women in recovery; and
- Self-disclosure is a process and can inspire others to focus on prevention of FASD.

Hope and Action: Shaping Policies to Sustain Strategies that Prevent and Address FASD

Moderator: Kathy Jo Stence, Program Analyst, Bureau of Drug and Alcohol Programs, Pennsylvania Department of Health; NAFSC Member

Speakers:

- Eileen Bisgard, JD, Project Director, 17th Judicial District, Colorado Judicial Department
- Meghan Louis, FASD Program Director, Hennepin County Human Services and Public Health Department, Juvenile Justice Center

Session presenters shared approaches on how to work with State legislatures and judges to sustain FASD prevention and intervention services. Critical elements for sustaining FASD services in Colorado include having a legislative champion and knowledge of the legislative process. Formation of the Colorado FASD Commission was an early step that provided a successful base for other activities. The Commission has been strengthened and expanded in Colorado, and efforts to fund FASD diagnostic evaluations will continue. Data on the outcomes and State costs can be used to support legislation.

Children who come into the delinquency system benefit from having judges who are knowledgeable about FASD. An informed judiciary enables them to become the lead in the process for sustaining the FASD prevention and intervention programs. Judges are able to use established local resources and the local sentencing guidelines to fashion probation and protection plans for children.

The VOICE of Self Advocates with Fetal Alcohol Spectrum Disorders in Action (SAFA) Network

Speakers:

- Leigh Ann Davis, MSSW, MPA, SAFA Network Liaison; Program Associate, The Arc of the United States; Expert Panel Member
- Jasmine Suarez-O'Connor, SAFA Network Coordinator; Expert Panel Member
- Dianne O'Connor, New York State Office of Alcoholism and Substance Abuse Services Prevention; SAFA Network Support Person

This session started with a *human treasure hunt* designed to help participants learn about each other. Participants shared their expectations for the conference before learning more about what it means to be a self advocate. They viewed three short video stories featuring individuals with an FASD who successfully addressed personal and community issues through self advocacy. The group also discussed issues that the SAFA Network might address in the future.

Day 1 Breakout Sessions—the Second Round

Taking Flight: An FASD State System in Action

Moderator: Shelly L. Bania, CPC-R, ICPS, FASD Program Specialist/Prevention Coordinator, Community Assessment Referral Education (CARE); BFSS Planning Committee Member

Speakers:

- Trisha Hinson, MEd, CMHT, FASD State Coordinator/State Project Director, Mississippi Department of Mental Health; NAFSC Member
- Sandra Parks, Director, Division of Children and Youth Services, Mississippi Department of Mental Health
- Millicent Ledbetter, Yazoo County Director, Warren-Yazoo Mental Health Services

Participants were provided with a description of the Mississippi State System of Care, the benefits of a comprehensive system of card, and steps their States can take to develop their own systems of care. The Mississippi State System of Care (Interagency Coordinating Council for Children and Youth, Interagency System of Care Council, and the Making A Plan Teams—MAP Teams) provides for the development and implementation of a coordinated interagency system of necessary services and care for children and youth up to age 21 with serious emotional disorders who require multiple programmatic services and who can be successfully diverted from inappropriate institutional placement. MAP Teams—which include FASD information dissemination, training, screening, referrals, and treatment interventions—serve as the initial point of contact for local communities. Mental health services for children include intake assessment, FASD screening, referral for evaluation, and treatment/intervention planning for those children who are diagnosed with an FASD. The available services include treatment planning, psychiatric/psychological assessments, parent education and support, case management or intensive case management, individual and family therapy, an Adolescent Offender Program, day treatment, and outdoor therapy. The University of Mississippi Medical Center Child Development Clinic provides diagnostic evaluation.

Day 1: The Second Round of Breakout Sessions

- Taking Flight: An FASD State System in Action
- Creating Change: The Big Picture on Grassroots Advocacy in Alcohol Policy
- Collaboration and Caring: Changing Social Norms by Engaging Prenatal Care Providers in Your State
- Connecting with Native American Communities to Build Comprehensive Systems of Care Inclusive of Tribal FASD Task Forces and Coordinators
- No Space in Time: A Moment in My Life with the Native American Flute—Sharing a Personal Story and Flute Demonstration (a session for SAFA Network members and their support persons only)

The Warren-Yazoo Pilot FASD Preschool Day Treatment program was highlighted as one of the programs available in the system. It serves children ages 3-5 who have been prenatally exposed to alcohol. Components of the program include a child-friendly environment and structured schedule, healthy snacks and meals, transportation, parenting classes, case management, assistance with transition to regular school placement, and health screenings.

Creating Change: The Big Picture on Grassroots Advocacy in Alcohol Policy

Moderator: Margo Singer, MPA, Addictions Program Specialist II, New York State Office of Alcoholism and Substance Abuse Services; NAFSC Vice Chair

Speakers:

- Linda Chezem, JD, Professor, Purdue University and Indiana University
- Robert S. Pezzolesi, MPH, Founder/CEO, New York Center for Alcohol Policy Solutions/New York Alcohol Policy Alliance
- Marissa Lang, Public Policy Manager, MOFAS

As a judge for 22 years, Dr. Chezem shared that she had seen many unintended outcomes of laws. She explained that bad laws (and policy) do not meet either the needs of the community or those persons who are affected by an FASD. Research on the effects and consequences of laws affecting those with an FASD is limited. She concluded by providing an overview of a taxonomy to consider public health laws including FASD-related statutes.

Mr. Pezzolesi provided an overview of the case for integrated FASD policy. He defined an integrated policy approach as one that is consistent within the broader public health model of alcohol problem prevention. He cited multiple studies suggesting that targeted alcohol prevention and intervention strategies can be combined with population-level strategies to prevent FASD. He suggested the following action steps:

- Support efforts in your State to enact evidence-based, public health alcohol policies.
- Connect and collaborate with the broader alcohol prevention/treatment/recovery community
- Push back against industry marketing attempts to increase consumption among girls and women.
- Refuse industry money.

Ms. Lang provided an overview of the MOFAS mission and goals. She suggested that FASD grassroots development depends upon (1) parents who want to make a difference, (2) advocates who know their issue, and (3) collaboration with key organizations. Creating an advocacy network involves strategies for recruitment, engagement, and empowerment.

Collaboration and Caring: Changing Social Norms by Engaging Prenatal Care Providers in Your State

Moderator: Jerome A. Romero, Director, New Mexico Statewide Prevention Project, University of New Mexico; NAFSC Chairman; Expert Panel Member

Speakers:

- Kendra Nelson, Community Grants Coordinator, MOFAS
- Emily Gunderson, Communications Director, MOFAS

MOFAS was awarded a community grant to fund seven clinic sites in Hennepin County to conduct alcohol screening and brief intervention. Their first cycle included developing a prenatal alcohol screening tool to be implemented in the sites. The second cycle expanded on the screening tool and incorporated it into an electronic medical record. They also created an action plan, developed a resource directory, and found other ways the clinic can share the message. As for education, the grants will utilize peer-to-peer education, CDC Regional Training Center Training of Trainers for medical providers, and free online continuing medical education credits. Key to these programs is the engagement of providers, and to that end MOFAS is developing campaigns to educate providers on the vital role they play in educating and influencing women about the importance of abstinence from alcohol during pregnancy.

Connecting with Native American Communities to Build Comprehensive Systems of Care Inclusive of Tribal FASD Task Forces and Coordinators

Moderator: Candace Shelton, MS, Senior Native American Specialist, SAMHSA FASD Center for Excellence

Speakers:

- Louise S. Ashkie, Program and Project Specialist, Navajo Nation FASD Project, Department of Behavioral Health Services, Arizona/New Mexico; American Indian/Alaska Native/Native Hawaiian Expert Panel Member; NAFSC Member
- Ernest Harry Begay, Traditional Practitioner, Navajo Regional Behavioral Health Board, New Mexico
- Gary Quinn, Health and Human Services Director, Tohono O'odham Nation, Arizona

There is currently only one FASD Coordinator in Indian Country, serving the Navajo Nation. About 10 years ago, FASD was a line item in the budget for Indian Health Services, with funding for an FASD Coordinator for every tribe, but because of changes to funding, money now goes to the tribes with no specific FASD designation. Some recent prevention efforts in Native communities have included a prevention education program directed toward high-risk teens, youth, and expecting mothers, and an FASD Peer Educator program for youth between the ages of 11 and 15.

Traditional beliefs are incorporated into FASD prevention and treatment approaches and all are provided within the context of the immediate and extended families. Spirituality, prayers, and song are integrated in the healing approach.

The Tohono O'odham Nation has begun incorporating motivational interviewing into FASD prevention as well as in other programs/efforts, including domestic violence, child welfare, special needs, probation, and within Native families as positive communication tools for parents. An FASD task force was recently developed within the Tohono O'odham Nation to bring together legislative leaders, district leaders, and Tribal and health departments. They are in the process of developing mission and vision statements as well as identifying the roles/needs of each FASD task force member. They are also seeking funding for a full-time FASD Coordinator.

No Space in Time: A Moment in My Life with the Native American Flute—Sharing a Personal Story and Flute Demonstration

Speaker: Morgan Fawcett, Native American Flute Player, SAFA Network Member

Morgan Fawcett gave participants an overview of his life with FASD, including the ongoing physical pain that he suffers. He shared that the ability to manage stress is extremely important to someone with an FASD and that he uses the flute for this purpose—playing in between classes or before tests to improve his ability to focus at school. Mr. Fawcett then presented SAFA members with their own flutes and gave them an hour-long music lesson. He encouraged them to use the instrument as he does—for centering himself and reducing stress.

Day 2 Breakout Sessions

As with Day 1, participants chose one of four available breakout sessions. SAFA Network members and their support persons once again attended a closed session specifically developed for their group.

Improving Outcomes by Strengthening Recovery

Moderator: Peggy Combs-Way, Director/Trainer/Parent Advocate, CalFAS; BMN Member; BFSS Planning Committee Member

Speakers:

- Mary C. DeJoseph, DO, Physician/Consultant, New Jersey Northeast FASD Education and Research Center; Expert Panel Member
- Joyce L. Washburn, MPA, Consultant/Trainer, Michigan
- Cathy Worthem, Program Manager, Arbor Circle Corporation

The presenters discussed improving outcomes by strengthening recovery. Dr. DeJoseph focused on the brain in addiction and recovery, including a review of the major features and progression of addiction, the structures of the brain, and understanding addiction as a chronic, metabolic disease of the brain and nervous system. Although some of the effects on the brain from chronic alcohol use are reversible and brain function may improve during recovery, the effect on an alcohol-exposed fetus is permanent. Pregnant women with addiction are in critical need of a holistic approach to addiction and recovery.

Day 2: Breakout Sessions

- Improving Outcomes by Strengthening Recovery
- Faith in Collaboration: An Ohio Perspective on Growing a Local FASD System
- Planning for Renewal: Integrating FASD Prevention and Intervention Services for Successful Sustainability
- Evolving with the Challenges: FASD Regional Training Centers Present Success Stories from the Field
- Living with an FASD (a session for SAFA Network members and their support persons only)

Ms. Washburn spoke about understanding the concepts of a recovery-oriented system of care and different kinds of prevention strategies. A recovery-oriented system extends beyond abstinence or symptoms management to helping people achieve full, meaningful lives in the community. Post-treatment continuing care services are an integrated part of the system of care.

Ms. Worthem discussed local models of prevention in treatment settings. Michigan has several women's services programs at Arbor Circle, including the Family Engagement Program, the Parent-Child Assistance Program (P-CAP), and Women's Project Access. These programs use a two-pronged approach of eliminating or reducing alcohol use and increasing effective use of contraception.

Faith in Collaboration: An Ohio Perspective on Growing a Local FASD System

Moderator: Melinda S. Norman, Ohio FASD Statewide Coordinator, Ohio Department of Alcohol and Drug Addiction Services; NAFSC Member; BFSS Planning Committee Member

Speakers:

- Andrea Hoff, GPC, OCPS II, Program Coordinator, Montgomery County Office of Family and Children First
- Sister Mary Sartor, Executive Director, Double Arc, NOFAS-Ohio
- Sister Suzette Fisher, MEd, EdS, FASD Specialist, Double Arc, NOFAS-Ohio

Ms. Hoff is very involved in facilitating connections between agencies, and drew on her skills as community organizer to organize an FASD Task Force. She highlighted lessons learned and

explained the importance of a *doer* perspective rather than a *thinker* perspective. She cited accomplishments of the FASD Task Force and concluded with tips for sustainability.

Sister Mary Sartor provided an overview of the mission and history of the Double Arc program, a Toledo-based nonprofit founded to help children struggling in school. She explained that a system of support must be developed around individuals with an FASD. Systems of support include family, education, medical, housing, judicial, employment, mental health, and community (including faith-based organizations).

Sister Suzette Fisher described the 2001-2004 Triumph Curricula developed by Double Arc. The curricula were developed to educate parents and teachers about FASD. The parent series is a 6-week program for birth and foster parents. The program includes intake, screening, and consultation (face-to-face, e-mail, phone). The teacher series is comprehensive and can be adapted for use in a school setting. Sr. Fisher also described Double Arc's influence at the State level via activities such as meeting with Ohio's First Lady Hope Taft, joint collaborations with the Ohio Department of Health, and town hall meetings.

Planning for Renewal: Integrating FASD Prevention and Intervention Services for Successful Sustainability

Moderator: Laura Nagle, CPP, FASD Coordinator, Bluegrass Regional Prevention Center; NAFSC Member; BFSS Planning Committee Member

Speakers:

- Trisha Hinson, MEd, CMHT, FASD State Coordinator/State Project Director, Mississippi Department of Mental Health, NAFSC Member
- Jerri Avery, Director, Division of Substance Abuse Prevention, Mississippi Department of Mental Health

Since 2003, Mississippi has been working to incorporate FASD prevention and intervention into the permanent structure of their mental health system. They have made significant progress through avenues such as operational standards, State-level regulatory or policy actions, strategic planning, and ongoing education in the effort to build FASD permanency at all levels of service. Deliberate steps have been taken to ensure permanence of the FASD screening, diagnosis, and treatment of children in Mississippi. There is also a multi-strategy prevention plan focused on dramatically decreasing the number of women who use alcohol while pregnant.

Session presenters shared efforts that had limited success as well as current plans and strategies that are being designed and implemented to ensure a higher degree of success; discussed the effective use of both mandatory and voluntary plans to build and strengthen the FASD statewide system; and highlighted successful methods for partnering within a single agency as well as across multiple agencies and programs to build a strong, functional, sustainable FASD system that works.

Evolving with the Challenges: FASD Regional Training Centers Present Success Stories from the Field

Moderator: Debra Kimball, MSN, RN, Maternal Health Nurse Consultant, Michigan Department of Community Health; NAFSC Member

Speakers:

- Leigh E. Tenkku, PhD, MPH, Director for Research, Saint Louis University
- Carmela Joy Hayes, Program Coordinator, Meharry Medical College Department of Family & Community Medicine
- Carolyn Szetela, PhD, Associate Professor, Meharry Medical College Department of Family & Community Medicine

The speakers provided information on two regional FASD training centers funded by CDC. The Midwest Regional Fetal Alcohol Syndrome Training Center (MRFASTC) and the FASD Southeast Regional Training Center (FASD Southeast RTC) are each designed to train and support health professionals, and to incorporate FASD curricula into the training programs at each grantee's university or college and into the credentialing requirements of professional boards.

MRFASTC had positive outcomes from their train-the-trainer model. They are now ready to create and train teams throughout the region and train new speakers. A treatment program, *Partners for Success*, based at the St. Louis University Department of Family and Community Medicine, is a research initiative designed to provide an innovative intervention for children with an FAS/FASD.

FASD Regional Training Centers, funded by the Centers for Disease Control and Prevention, continue to provide training for medical and allied health professionals and medical students on the prevention, identification, and treatment (management) of FASD.

The FASD Southeast RTC is charged with developing, implementing, and evaluating FASD curricula for health providers, and disseminating implementation of the Competency-Based Curriculum for health providers. They also use the successful train-the-trainer model. Several approaches were used to integrate knowledge, skills, and attitudes into the training, including videotapes of medical students' simulating an FASD encounter, and review of media messages as teaching opportunities to raise awareness and to promote FASD awareness.

Living with an FASD

Speakers:

- Dan Dubovsky, MSW, FASD Specialist, SAMHSA FASD Center for Excellence
- Robert Wybrecht, SAFA Network Coordinator; Expert Panel Member

Mr. Dubovsky explained the areas of the brain most often affected by an alcohol-exposed pregnancy, and how that brain damage affects everyday interactions and reactions. He encouraged the group to become more self-aware and suggested positive ways to approach their challenges. Mr. Wybrecht talked about the successes he has had and independence he has gained in his life by following Mr. Dubovsky's recommendations. He told the group of specific measures he uses to help compensate for poor memory and organization. Both speakers also discussed the strengths that persons with an FASD possess and encouraged the group to cultivate and use them properly.

AFFILIATED MEETINGS

To aid in the development of a comprehensive system of care for individuals with an FASD and their families, the Center establishes support groups, grassroots organizations that affect policy change, and panels of experts to guide the Center's work. These groups generally meet at BFSS, as well, and include:

- The Birth Mothers Network;
- The National Association of FASD State Coordinators;
- The FASD Subcontractors;
- The Center's overall Expert Panel;
- The American Indian/Alaskan Native/Native Hawaiian Expert Panel; and
- The Self Advocates with FASD in Action Network.

This year, the Birth Mothers Network annual meeting was held apart from the BFSS Conference. The group held both its annual meeting and a peer training for their Speakers Bureau in January. There are currently 16 active speakers in the BMN Speakers Bureau. Members of this group have spoken before legislators and State FASD task forces, in treatment centers and domestic violence shelters, at schools, and even as part of international panels on FASD.

Below are brief synopses of the work accomplished at the affiliated meetings held May 10th and 11th in Phoenix.

National Association of FASD State Coordinators—Tuesday, May 10, 2011

NAFSC's mission is to promote prevention, treatment, and care systems for FASD in the United States through collaboration with systems within respective States and among member States. It includes officially designated FASD Coordinators from 24 States, the District of Columbia, and the Navajo Nation who, as part of a formal role, coordinate FASD activities within their State. NAFSC provides members with opportunities to share knowledge/expertise, experiences, and resources among peers. It uses subcommittees to further the work of the group.

NAFSC's agenda included a report on State FASD activities and updates from the Birth Mothers Network, SAFA Network, and the National Prevention Network. Current subcommittees are also discussing ways to engage providers, and get pharmaceutical manufacturers to include warning labels inside pregnancy test kits. The Primary Care Subcommittee recently drafted a list of approved FASD resources for providers. In addition:

- Dan Dubovsky, MSW, the Center's FASD Specialist, provided an update on the Center's trainings and encouraged Coordinators to attend trainings, if accessible, in order to continue including the most current information for trainings they may provide. Mr. Dubovsky and the group discussed ways State Coordinators can be notified when the Center is holding trainings in their State. Additionally, Mr. Dubovsky confirmed that the Center will provide a training schedule on the NAFSC Web page.
- Kathleen T. Mitchell, MHS, LCADC, Vice President and National Spokesperson for NOFAS facilitated a discussion on a potential ways NAFSC can establish a non-profit status in collaboration with NOFAS. Ms. Mitchell provided three possible opportunities, and NOFAS and NAFSC members discussed the benefits and challenges for each.

The group continues to assist non-member States in establishing their own statewide FASD coordinator to increase NAFSC's membership and presence across the country. NAFSC also works to establish strong partnerships with national organizations that supports NAFSC's overall mission.

NAFSC meets quarterly (once face-to-face in conjunction with BFSS), and will meet again via teleconference in August 2011.

Expert Panel—Wednesday, May 11, 2011

The Center's Expert Panel's agenda included an update on the work of the Center and its 23 subcontractors, as well as an overview of the Center's Learning Communities Initiative and updates from the Native Expert Panel, NAFSC, the SAFA Network, the National Prevention Network, the CDC, and NIAAA. In addition:

- Vinitha Meyyur, PhD, the Center's Senior Evaluator, provided an overview of recent activities related to the development of the FASD TIP. TIP Co-Chairs Melinda M. Ohlemiller, MA, and Sterling K. Clarren, MD, FAAP, facilitated discussion on the revised TIP outline.
- Jill G. Hensley, MA, Program Manager, delivered an update on the activities of the Center's 23 subcontractors (more information provided below). Feedback from the Panel stressed the need to utilize the data being generated by the subcontractors to identify gaps in services for individuals with an FASD as well as pregnant women, and expand the available background information related to these populations (e.g., stage of pregnancy when entering treatment, education level, rates of successful follow-up).
- Dr. Clarren, Chief Executive Officer and Scientific Director of the Canadian Northwest FASD Research Network, discussed recent Canadian collaboration to advance the prevention of FASD.

The meeting concluded with a discussion of action steps related to the final year of the Center's contract, and how the Panel can sustain its work. A subcommittee was established to address this issue. Ms. Gass suggested that the subcommittee advise the Center on what they should compile, document, or record—products that would inform whatever comes next.

The Expert Panel meets face-to-face twice annually, and will meet again in November 2011 in the Washington Capital Area.

FASD Subcontractors—Wednesday, May 11, 2011

The Coordinating Center of the FASD Center for Excellence oversees 23 subcontracts that are implementing prevention and diagnosis and intervention programs. The programs include States, tribal courts, juvenile dependency and delinquency courts, and local providers.

The subcontractor meeting at BFSS was structured around three sets of breakouts sessions, two in the morning and one after lunch. The breakout sessions were divided into four groups; the 15 prevention subcontractors split out by specific program (i.e., Screening and Brief Intervention, Project CHOICES, and P-CAP), and the eight diagnosis & intervention subcontractors. The first set of breakouts was focused on Year 3 (2009-2010) accomplishments, including data presentations, annual report planning, and monitoring and uses of data. The second set of breakouts, again broken out by the specific programs, centered on Year 4 (2010-2011) planning.

After lunch, the attendees split into State, local, and juvenile court groups to discuss the integration of lessons learned, success stories, and hold moderated group discussions. Some of the lessons discussed included:

- Providing comprehensive training for new staff;
- Including checklists for new hires so that expectations are communicated clearly;
- Reviewing policies and procedures;
- Assigning mentors for new employees;

- Providing new employees with feedback at a 3-month evaluation and after a 6-month probation period;
- Discussing implementation early on and provide implementation workshops;
- Exploring alternate funding sources to provide county-wide training; and
- Sending staff to Train-the-Trainers events for FASD.

For the closing plenary, the group gathered to hear from Sharon L. Dorfman, ScM, CHES, President of SPECTRA and a subcontractor. Ms. Dorfman provided strategies for sustainability planning—an important focus for the final contract year (2011-2012).

American Indian/Alaskan Native/Native Hawaiian Expert Panel—Tuesday, May 10, 2011

The American Indian/Alaskan Native/Native Hawaiian Expert Panel (Native Expert Panel) meeting opened with a blessing and story by Delmar Boni of the Apache Nation. In addition to comments from SAMHSA and the Center, an FASD research update was provided by Jennifer Thomas, PhD, Associate Professor from the Center for Behavioral Teratology in the Department of Psychology at San Diego State University. Center staff discussed traditional treatment and gave updates on the Native Resource Kit and the Inventory of Native Programs. Kendra King Bowes, MPA, a Project Director for Native American Management Services, shared information on the three upcoming Native Leaders Meetings that will assemble members of the Native community who are in positions to influence policy relative to FASD prevention and treatment. In addition, Jeri Museth, MSW, Native Expert Panel Co-Chair, provided a presentation on FASD and Sexuality.

The meeting closed with the viewing of four digistories—computer-based short biographies—of individuals with an FASD. The group also commended Native Expert Panel member Ginny Wright, MS, who was recognized as 2011 Parent of the Year by SPIN—the Special Parent Information Network—for her work raising awareness of issues related to FASD.

The Native Expert Panel meets face-to-face twice annually, and will meet again in November 2011 in the Washington Capital Area.

Self Advocates with FASD in Action Network—Wednesday, May 11, 2011

The SAFA Network kicked-off its first official meeting, led by SAFA Network Coordinators Rob Wybrecht and Jasmine Suarez-O'Connor. (Leigh Ann Davis of The Arc of the United States serves as the SAFA Network Liaison.) After welcoming remarks from Mr. Dunbar-Cooper and Ms. Gass, the facilitators took turns guiding participants through a presentation on the Network's creation, membership, and goals. The underlying premise for self-advocacy, as well as for SAFA, is *Nothing about me without me*, a declaration of the individual's right to have a voice in his/her own care and in how he/she is perceived, approached, and delivered services by others. SAFA also hosted a display during the Opening Poster Session as SAFA member Morgan Fawcett, a Native American flute player, provided music.

CONCLUSION

State Planning

Shortly after the BFSS Conference, State representatives are asked to complete two questionnaires about the level of FASD activity in their State, as well as submit an FASD State Plan (as resources allow). The Center uses this information to assist with supporting and working with the States throughout the year to further develop their plans and move toward accomplishing their long-term goals.

This year, based on feedback from State Coordinators and lead State contacts, the Center streamlined the process by revising the questionnaires, State Plan, and follow up process. This included rephrasing and providing new examples to better clarify the questions.

Action Steps

As with each BFSS event, the Center will pursue certain action steps following the BFSS 2011 Conference:

- Review submitted State Plans and questionnaires to determine what follow-up is necessary to assist States in meeting their goals (e.g., resource suggestions, mentoring, TA).
- Follow up with States who are seeking to establish an FASD State Coordinator position—since the BFSS Conference, Alabama has appointed an FASD State Coordinator.
- Pull together lessons learned from the planning process and meeting evaluations to refine and improve next year's process.
- Hold a staff debriefing session on lessons learned from the BFSS 2011 Conference to ensure that next year's conference is equally if not more successful.
- Update the Center's Web site with information from the conference, including the meeting summary, presentations, speaker biographies, photographs, and participant lists.
- Provide all conference participants with a CD with information from the conference, including presentations, speaker biographies, and a participant list of actual attendees.

In addition, a number of specific suggestions emerged, including the need to provide advance information about the BFSS 2012 Conference via social marketing media, and encouragement to accommodate even more conference attendees at next year's conference. As always, the Center will incorporate this and all participant feedback in upcoming planning sessions and product development in an effort to continue to support the needs of the field.

Outcomes

Each BFSS Conference is evaluated by participants to gather their thoughts on the agenda, the speakers, the site, and the usefulness of the information shared, and also to elicit recommendations for the next event. In addition to formal evaluation findings (beginning on the following page), positive trends emerge each year. For 2011, these include:

- **High participation**—Attendance at this year's BFSS Conference was up by 20% from last year's event. (Note that the 2010 Conference in Nashville coincided with a terrible flood, which caused many participants travel delays—and in some cases, cancellations.) Generally good weather and the positive reputation of this conference in the field made for an all-time-high turnout.
- **The continued growth of FASD-related organizations**—Both NAFSC and the BMN continue to increase in size, the SAFA Network formalized its organization and is looking to expand membership, and, beginning with the Diagnostic Learning Community, which started in late 2009 among the Center's subcontractors, four additional learning communities have been/are being formed.

- **Increased collaboration—**In the past year, the Birth Mothers Network expanded its Speakers Bureau and reached out to State NAFSC representatives to offer outreach to other birth mothers and to assist with trainings and advocacy in their States/regions; members of the Center's Expert Panel and Native Expert Panel held a joint meeting to discuss ways in which they could support each other's missions and goals; Mr. Wybrecht of the SAFA Network is working to get representation of individuals with an FASD on State FASD task forces; and the subcontractors have all found creative ways to grow their efforts and collaborate with each other. The Center's affiliated groups continue to focus on their missions and look at ways to increase their reach and ensure their sustainability, by looking to the resources and support available through their peers and through the Center.

With this, the fourth year of the Center's 5-year contract, a major thread through the BFSS 2011 Conference was that of sustainability—subcontractors discussed strategies for sustainability at their closing plenary and are in the process of developing individual plans for the continuation of their work, a NAFSC subcommittee is exploring options for operating under a non-profit arrangement, and in the closing plenary, Ms. Hinson shared some of Mississippi's strategies for sustaining FASD system of care. As in previous years, the BFSS Conference served to assist States in various stages of FASD systems of care development with ideas, resources, and contacts.

As we move toward 2012, the Center will continue to support the needs of the States through its affiliated groups, through the resources provided on www.fasdcenter.samhsa.gov, through the sponsorship of learning communities, and through direct training and technical assistance, all vital elements of meeting the Center's ultimate goal: The continued growth and ongoing presence of a comprehensive system of care for individuals with an FASD.

APPENDIX A: CONFERENCE EVALUATION

Introduction

The evaluation component for the BFSS 2011 Conference focused on determining the attendees' overall level of experience of certain attributes of the meeting, such as quality and clarity, information sharing, networking opportunities, and applying lessons learned to work situations. In addition, attendees were asked to provide feedback on the usefulness of each of the sessions.

Methods

An evaluation form was designed to elicit feedback from attendees (Appendix B). Evaluation forms were provided to all attendees and filled out and returned to Center staff at the end of the meeting. Completed evaluation forms were checked for data accuracy, followed by data entry and analysis. For all closed-ended questions, responses were tallied and percentages calculated. A content analysis was performed for the open-ended responses.

Evaluation Questionnaire

The questionnaire was designed to include both close-ended and open-ended questions. The first question was designed to get respondents' ratings on general aspects of the meeting. The second question regarded the usefulness of the general and breakout sessions.

Attendees were asked to respond to open-ended questions on the following topics:

- The most useful part of the meeting;
- Plans to use what they learned at the conference in their work; and
- Topics or speakers for future BFSS meetings.

Evaluation Results

A total of 135 respondents submitted completed evaluation forms. Quantitative and qualitative results are presented below.

Quantitative Results

Respondents' ratings of the conference overall, and of the sessions held during this event, are presented in Tables 1 and 2 below. The percentages of respondents shown in these tables are based on the actual numbers of those who answered a particular question, as shown in the last column of Table 1 and Table 2.

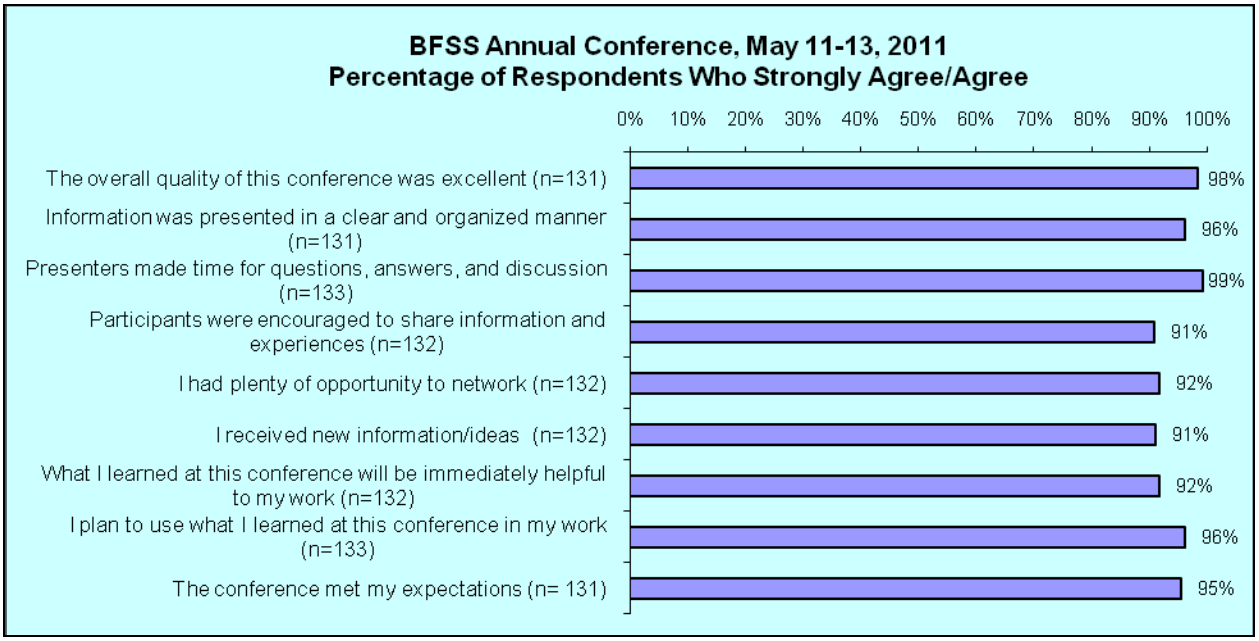
Table 1—General Assessment of the Conference

Item	Strongly Disagree	Disagree	No Opinion	Agree	Strongly Agree	Total
The overall quality of this conference was excellent.	0 (0%)	0 (0%)	2 (2%)	36 (28%)	93 (71%)	131 (100%)
Information was presented in a clear and organized manner.	0 (0%)	0 (0%)	5 (4%)	42 (32%)	84 (64%)	131 (100%)
Presenters made time for questions, answers, and discussion.	0 (0%)	0 (0%)	1 (1%)	47 (35%)	85 (64%)	133 (100%)
Participants were encouraged to share information and experiences.	0 (0%)	3 (2%)	9 (7%)	43 (33%)	77 (58%)	132 (100%)
I had plenty of opportunity to network.	0 (0%)	7 (5%)	4 (3%)	50 (38%)	71 (54%)	132 (100%)

I received new information/ideas.	0 (0%)	1 (1%)	2 (2%)	50 (38%)	79 (60%)	132 (100%)
What I learned at this conference will be immediately helpful to my work.	0 (0%)	3 (2%)	8 (6%)	44 (33%)	77 (58%)	132 (100%)
I plan to use what I learned at this conference in my work.	0 (0%)	0 (0%)	5 (4%)	39 (29%)	89 (67%)	133 (100%)
The conference met my expectations.	0 (0%)	1 (1%)	5 (4%)	38 (29%)	87 (66%)	131 (100%)

Note: Due to rounding, sum may not add to 100 percent.

Figure 1—General Assessment of the Conference



As shown in Figure 1, respondents gave the conference a highly favorable assessment, with the vast majority (98 percent) rating it as excellent in quality and indicating that they planned to use what they learned in their work (96 percent). Almost all respondents also felt that the information presented was clear and well organized (96 percent) and most agreed that presenters made time for questions, answers, and discussion (99 percent).

When comparing the rating of this conference to the 2010 BFSS Conference in Nashville, Tennessee, the scores were slightly higher across all categories. Changes in ratings ranged from an increase of one percent (information presented in an organized manner and received new information) to an increase of nine percent (presenters made time for questions and discussion).

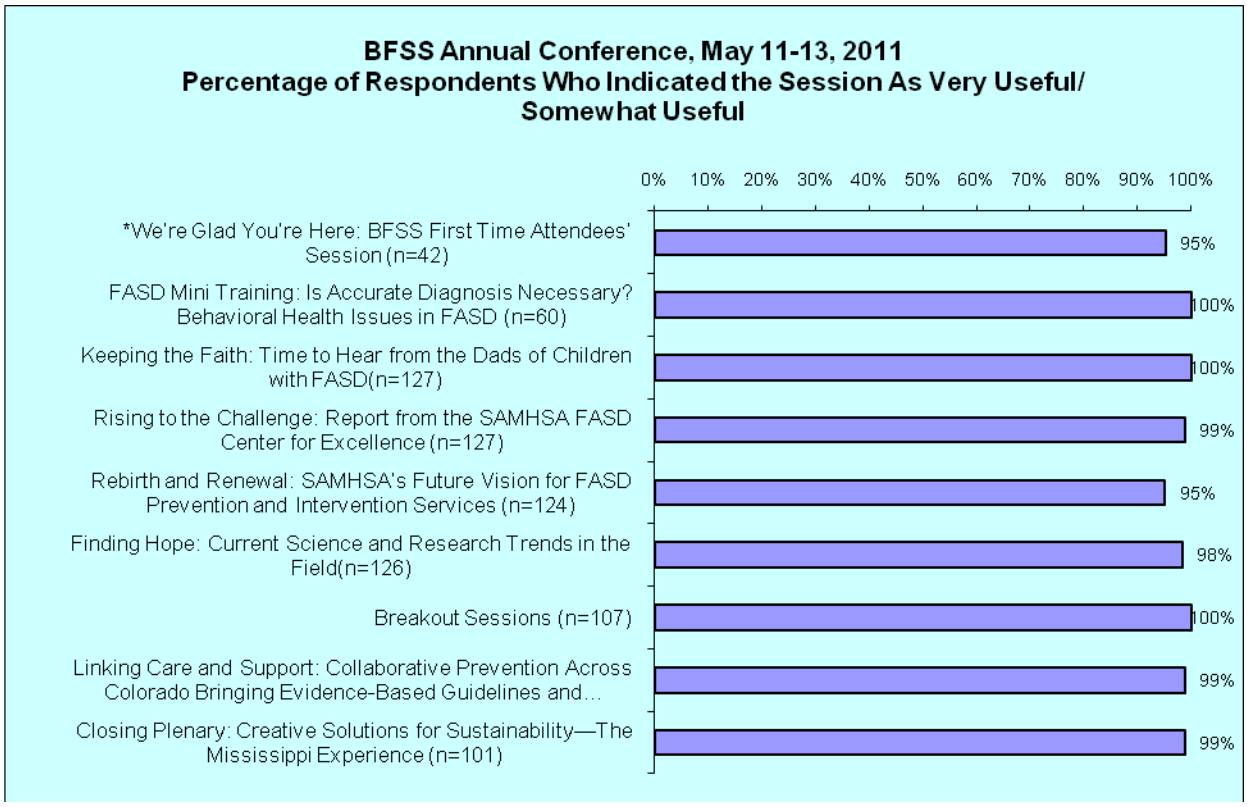
Table 2—Assessment of the Sessions

Please circle the number that matches your answer.	Not at All Useful	Not Very Useful	Somewhat Useful	Very Useful	Total
We're Glad You're Here: BFSS First Time Attendees' Session*	0 (0%)	2 (5%)	8 (19%)	32 (76%)	42 (100%)
FASD Mini Training: Is Accurate Diagnosis Necessary? Behavioral Health Issues in FASD	0 (0%)	0 (0%)	7 (12%)	53 (88%)	60 (100%)

Keeping the Faith: Time to Hear from the Dads of Children with FASD	0 (0%)	0 (0%)	18 (14%)	109 (86%)	127 (100%)
Rising to the Challenge: Report from the SAMHSA FASD Center for Excellence	0 (0%)	6 (5%)	50 (39%)	71 (56%)	127 (100%)
Rebirth and Renewal: SAMHSA's Future Vision for FASD Prevention and Intervention Services	0 (0%)	6 (5%)	57 (46%)	61 (49%)	122 (100%)
Finding Hope: Current Science and Research Trends in the Field	0 (0%)	2 (2%)	14 (11%)	110 (87%)	126 (100%)
Breakout Sessions	0 (0%)	0 (0%)	35 (33%)	72 (67%)	107 (100%)
Linking Care and Support: Collaborative Prevention Across Colorado Bringing Evidence-Based Guidelines and Research into Practice	0 (0%)	0 (0%)	47 (39%)	74 (61%)	121 (100%)
Working Lunch and Closing Plenary: Creative Solutions for Sustainability—The Mississippi Experience	1 (1%)	0 (0%)	23 (23%)	77 (76%)	101 (100%)

***Session was encouraged for BFSS first timers.**
Note: Due to rounding, sum may not add to 100 percent.

Figure 2—Assessment of the Sessions



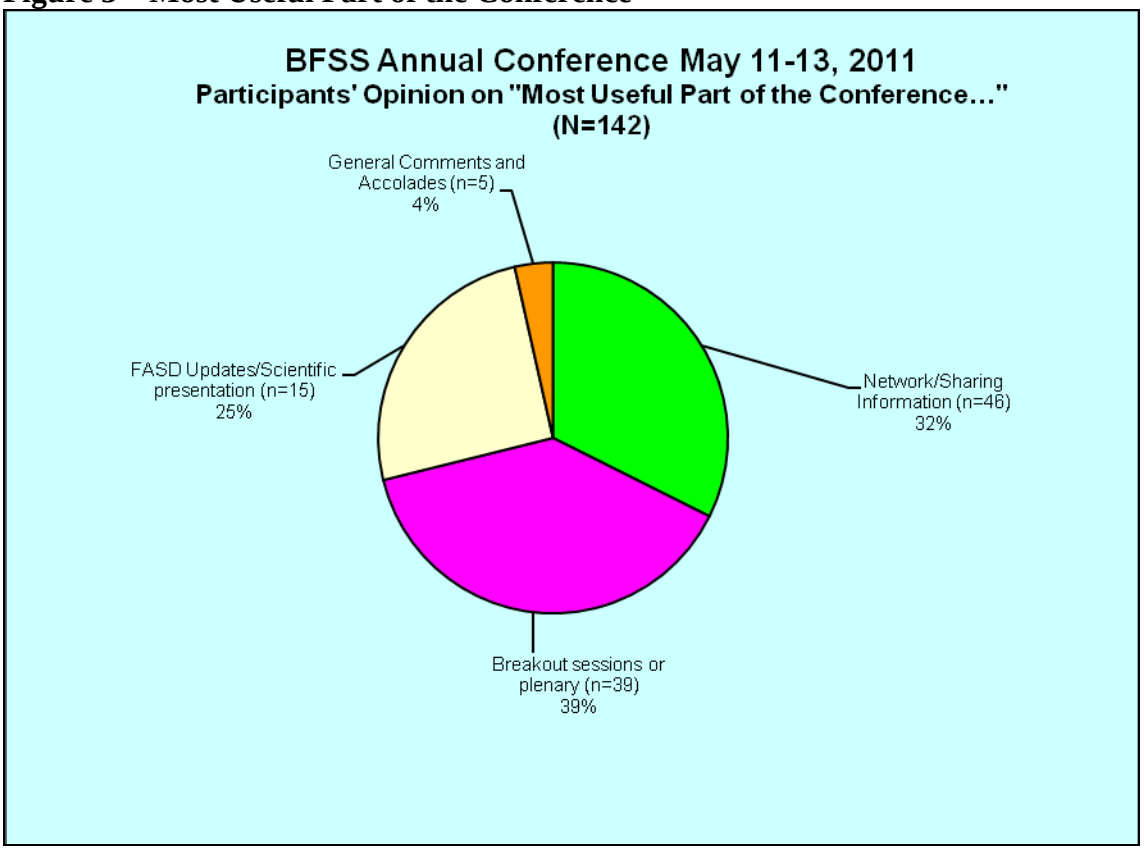
BFSS First Time Attendees' and was for the BFSS first timers.

As illustrated in Figure 2, the sessions that were rated as "very useful/somewhat useful" by the highest percentages of respondents were *FASD Mini Training* (100 percent), *Keeping the Faith: Time to Hear from the Dads of Children with FASD* session (100 percent), and the Breakout Sessions (100 percent).

Qualitative Results

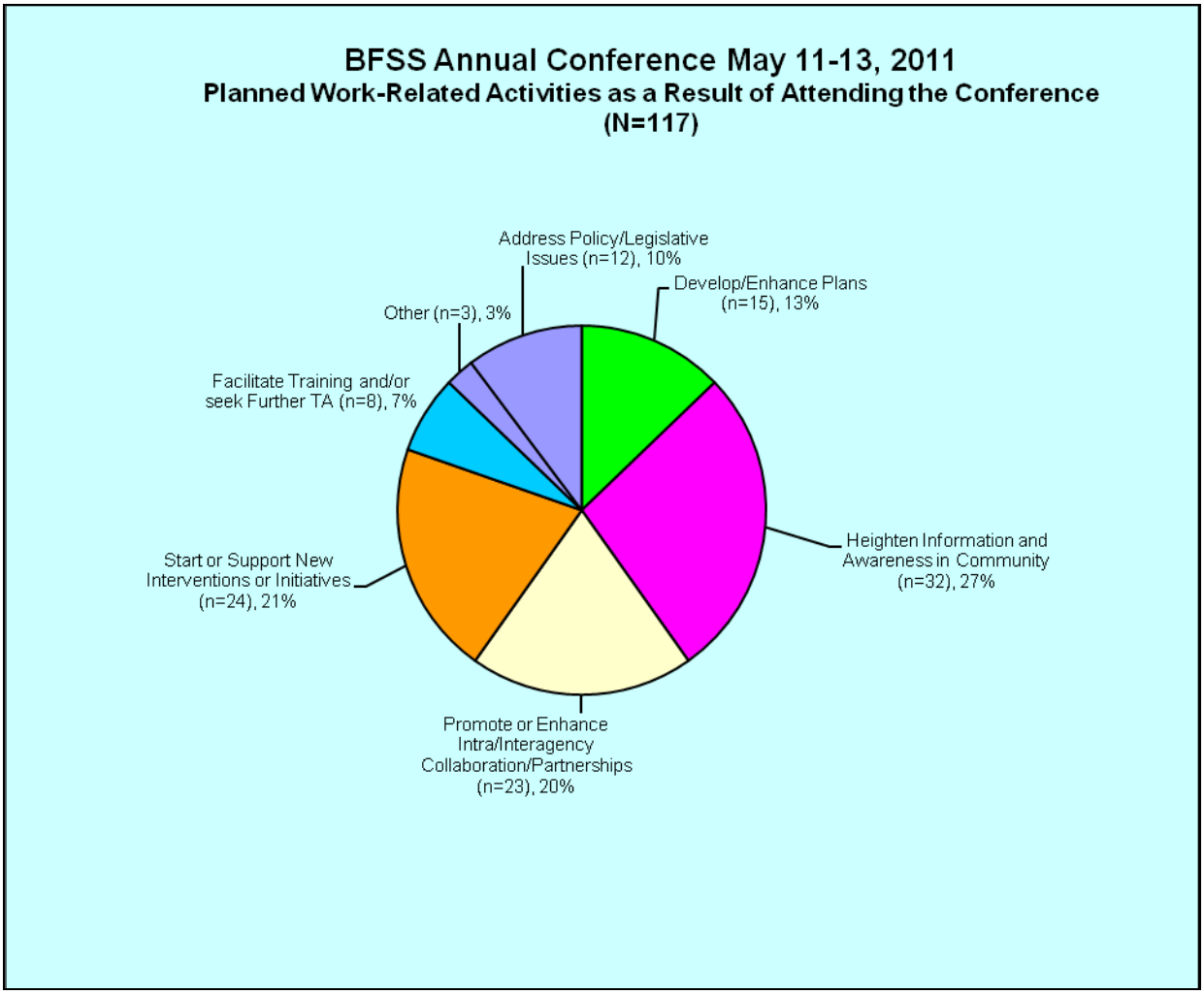
Respondents provided written comments about this conference to three open-ended questions. For each of the open-ended questions, responses were grouped under specific topic areas. The total number of responses within each topic area for each of the questions is represented in the pie charts on the following pages.

Figure 3—Most Useful Part of the Conference



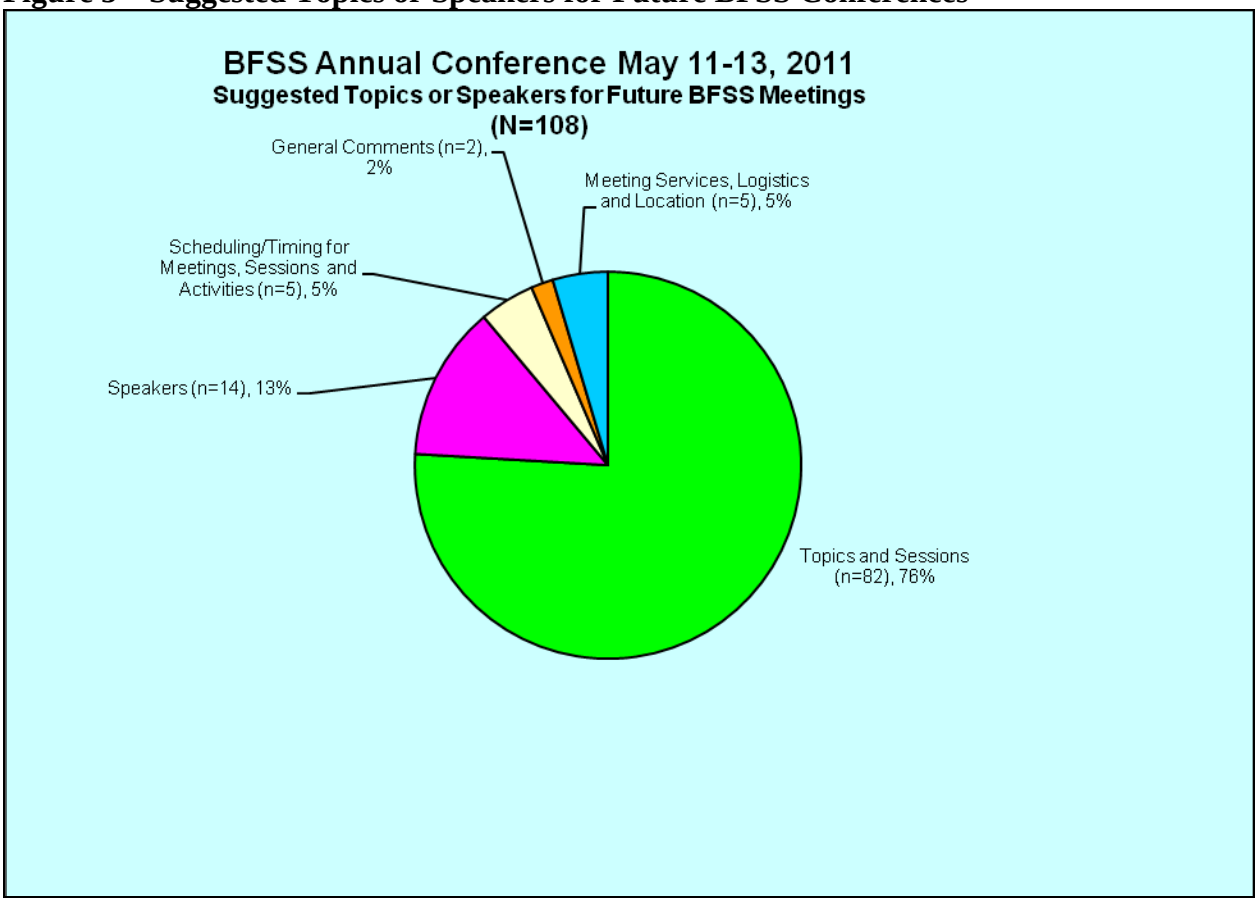
As presented in Figure 3, the majority (39 percent) of the responses indicate that participants found the breakout or plenary sessions to be the most useful. Thirty-two percent of the responses indicated the networking and sharing information to be most useful.

Figure 4—Respondents' Planned Work-Related Activities as a Result of Attending the Conference



Among the 117 responses received to this question, the most frequently reported priorities were to heighten information and awareness in the community (27 percent).

Figure 5—Suggested Topics or Speakers for Future BFSS Conferences



Of the 96 responses for suggestions for topics or speakers for future BFSS Conferences, the majority (76 percent), provided suggestions on new ideas for topics and sessions.

Evaluation Conclusions

Evaluation results presented above indicate that this conference was a success. Significant findings from the quantitative and qualitative data presented in Tables 1 and 2 and responses to the open-ended questions are as follows:

- Overall, 98 percent of the respondents rated the quality of this conference as excellent, and 99 percent agreed that presenters made time for questions, answers, and discussion.
- The vast majority of respondents (96 percent) felt that the information presented was clear and well organized, and that they intended to use this information when they got back to work (96 percent).
- The *FASD Mini Training, Keeping the Faith: Time to Hear from the Dads of Children with FASD* sessions, and the Breakout Sessions were viewed as the most useful components of the conference (100 percent).
- Thirty-nine percent of the responses indicated that the breakout or plenary sessions were the most useful part of the conference.
- The most frequently reported work-related plans were to heighten information and awareness in the community (27 percent).
- The majority of the responses (76 percent), on topics/speakers for future meetings, were new ideas for topics and sessions.

APPENDIX B: EVALUATION FORM

Building FASD State Systems (BFSS) Conference

Phoenix, Arizona
May 11-13, 2011

SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence

EVALUATION FORM

Date Completed: _____
Title/Position: _____

1. Have you attended a BFSS Conference in the past? Yes__ No__

2. To what extent do you agree with the following general statements about this conference:

Please circle the number that matches your answer.	Strongly Agree	Agree	No Opinion	Disagree	Strongly Disagree
The overall quality of this conference was excellent.	5	4	3	2	1
Information was presented in a clear and organized manner.	5	4	3	2	1
Presenters made time for questions, answers, and discussion.	5	4	3	2	1
Participants were encouraged to share information and experiences.	5	4	3	2	1
I had plenty of opportunity to network.	5	4	3	2	1
I received new information/ideas.	5	4	3	2	1
What I learned at this conference will be immediately helpful to my work.	5	4	3	2	1
I plan to use what I learned at this conference in my work.	5	4	3	2	1
The conference met my expectations.	5	4	3	2	1

3. How useful were the following sessions:

Please circle the number that matches your answer.	Very Useful	Somewhat Useful	Not Very Useful	Not At All Useful	Attended Session (Circle Yes or No)	
We're Glad You're Here: BFSS First Time Attendees' Session	4	3	2	1	Yes	No
FASD Mini Training: Is Accurate Diagnosis Necessary? Behavioral Health Issues in FASD	4	3	2	1	Yes	No
Keeping the Faith: Time to Hear from the Dads of Children with FASD	4	3	2	1	Yes	No
Rising to the Challenge: Report from the SAMHSA FASD Center for Excellence	4	3	2	1	Yes	No
Rebirth and Renewal: SAMHSA's Future Vision for FASD Prevention and Intervention Services	4	3	2	1	Yes	No
Finding Hope: Current Science and Research Trends in the Field	4	3	2	1	Yes	No
Breakout Sessions	4	3	2	1	Yes	No
Linking Care and Support: Collaborative Prevention Across Colorado Bringing Evidence-Based Guidelines & Research…	4	3	2	1	Yes	No
Closing Plenary: Creative Solutions for Sustainability—The Mississippi Experience	4	3	2	1	Yes	No

4. What was the most useful part of this conference for you? Please explain.

5. What are one or two things you plan to do in your work, based on what you learned at this conference?

6. What topics or speakers would you suggest for future BFSS Conferences?

Thank you for your feedback. Please drop in the evaluation box.